The Challenge of Treating Gay Men with AIDS

MICHAEL SHERAN, MD*

To appreciate the unique challenges of treating AIDS (acquired immunodeficiency syndrome) in gay men, we first must place the disease in the social and political context of the gay rights movement. Before 1969, the vast majority of lesbians and gay men were forced to lead double lives. Although a civil rights law banned discrimination against racial and ethnic minorities in employment, housing, and public services, gay people had no legal protections. Lesbians and gay men were outlaws; sexual activity between people of the same gender was illegal in all 50 states. Even the congregation of gay people in bars and clubs was prohibited by law. Police raids on gay establishments were commonplace. Finally, in 1969, one such raid on the Stonewall bar in Greenwich Village touched off a riot that spawned the gay liberation movement. No longer willing to passively accept discrimination, lesbians and gay men took to the streets and demanded the right to be open about their lives without fear of losing their jobs, their housing, or their children.

Then, as now, it took great courage to be open about being gay, and only a small minority of brave pioneers was willing to take the risks involved in being politically active. A small, vocal group of activists paved the way for the rest of the gay community and slowly, over more than a decade, managed to increase the visibility of gay people and decrease the stigmatization of homosexuality. The larger majority of gay people, although not necessarily on the

* Dr. Sheran is Attending Physician, AIDS Center Program, St. Vincent's Hospital, 32 W 18th St, New York, NY 10011, and Assistant Professor of Medicine, New York Medical College, Valhalla, NY.

front lines of the political fight, were nonetheless undergoing personal transformations. To varying extents, individual gay people began the process of "coming out" in their personal lives and telling their friends and families about their sexuality. The enormous relief of not having to hide or lead a clandestine double existence cannot be overemphasized. In the context of AIDS, it has a profound significance.

Much was accomplished during the first decade of the gay rights movement: sodomy statutes were repealed or struck down by courts in 25 states; antidiscrimination laws were passed in many cities and towns; and homosexuality gradually became more socially acceptable. However, the battle had just begun. Despite progress, the vast majority of Americans still felt great antipathy toward gay people, and discrimination remained legal in most of the country. In 1980, the election of Ronald Reagan bolstered the religious right, and a conservative backlash began. Most gay people still felt that they personally stood to lose more than they could gain by becoming political activists.

In 1981, a cluster of cases of Kaposi's sarcoma and *Pneumocystis carinii* pneumonia was reported among gay men in New York City and Los Angeles. It soon became apparent that a new disease had emerged. At first, it was called gay-related immunodeficiency (GRID); soon, it was renamed the acquired immunodeficiency syndrome. From then on, the lives of gay men and the nature of the gay rights movement were radically changed. Gay men with AIDS, who had earlier in their lives mustered the courage to go through the arduous process of "coming out," suddenly found themselves with a new secret and a new reason to fear discrimination. Gay men with AIDS who had not yet "come out" now faced the daunting task of telling family and friends that they were not only gay but had a highly stigmatized terminal illness. HIV (human immunodeficiency virus)-negative gay men suffered from fear of becoming HIV-infected themselves and from the pain of seeing their friends and lovers become debilitated and die. Gay people with and without AIDS suffered the pain of seeing governmental and public indifference to these deaths.

Our fear at first was that AIDS would erase what modest social and political gains gay people had made and that the epidemic would signal the death of the gay rights movement. However, while AIDS was used by anti-gay groups and politicians as a justification for discrimination and bigotry, the ensuing activism in many ways galvanized the gay rights movement. Gay men no longer could allow others to fight for their rights while believing that discretion, rather than activism, would protect them. The issues had changed. The fight was no longer for social acceptance and the right to be open without fear of discrimination. The fight was now literally a matter of life and death. The closet would not protect anyone from HIV. Gay people realized that the disease would not have spread so widely and with such public indifference had it not been for widespread bigotry against gay people.

In response, they took up political activity in record numbers and with unprecedented vehemence. The tactics changed. Polite marches, quiet fundraisers, and letter writing gave way to loud protests and civil disobedience. The names of newly spawned groups such as ACT-UP and Queer Nation reflect the anger and sense of defiance felt by these newly politicized activists. For many gay men, AIDS activism and gay activism became synonymous.

The AIDS epidemic has had a dual effect on public attitudes toward gay people. For those already filled with animosity toward gay men, AIDS was proof positive that homosexuality was intrinsically unhealthy and immoral. For others, however, AIDS led to a reassessment of beliefs about gay people. The deaths of well-known figures such as Rock Hudson, Liberace, and other notables forced the public to acknowledge that many of the people they most admire and respect are gay. The involvement of the entertainment industry in AIDS fundraising also has made it more acceptable to stand up for gay rights. While accepting an Academy Award for portraying a gay man with AIDS, Tom Hanks told a worldwide audience how much he admired his gay acting teacher. Most recently, the widely publicized admission by the Olympic diver, Greg Louganis, that he is both gay and has AIDS has challenged preconceived notions about gay men. In short, AIDS

has blown a giant hole in the closet and has put well-known faces on what had previously been only a label.

Activists have demanded, in many cases successfully, increased public funding for AIDS-related research, treatment, and social services. They also have demanded an end to public indifference to, discrimination against, and stigmatization of AIDS. Their work is far from finished, but the list of accomplishments is undeniable. By being vigilant watchdogs, AIDS activists have done much to reduce the homophobia and AIDS-phobia of health care providers and institutions. Perhaps most importantly, activists forced a reassessment of the way medical therapies are tested and approved. They made us acutely aware that the process of testing and approving new drugs had been painfully slow and tied up by bureaucracy. By repeatedly insisting that business as usual is unacceptable and that those dying of AIDS cannot wait, AIDS activists have brought about major changes in the system. Expanded access, compassionate use, and parallel track protocols, which make unapproved drugs available to those for whom approved therapies are ineffective, have become commonplace as result of AIDS activism. AIDS activists also have forced us to look at alternative treatments; it is no coincidence that the National Institutes of Health has established an office to investigate such alternatives.

How AIDS Has Affected Health Care

The politicization of AIDS presents unique challenges to physicians who treat gay men infected with HIV. There has been a general trend in this country away from the blind acceptance of the physician's word and toward patient participation in health care decisions. In no area is this trend felt more acutely than in the field of AIDS care. People with AIDS are acutely aware that current therapies often are only minimally effective and quite toxic. Gay-oriented periodicals and public access cable television implore AIDS patients to question their doctors about treatment and to demand full participation in their medical care. People with

AIDS are urged by the gay media to educate themselves about their illness, and the AIDS activist movement itself often provides this education in the form of articles, television programs, and community forums.

I have read these periodicals and watched these television shows. For the most part, they are informed and well balanced. However, some of what I see and read is inspired mostly by frustration and desperation and serves more as a means to vent rage than to inform, educate, or empower. This fringe of radical literature and programming sometimes borders on the verge of hysteria and paranoia. It often vilifies all physicians and health care institutions. Rather than objectively discussing the advantages and disadvantages of available treatments, all current treatment options are portrayed as poisons being marketed simply for profit or even as an intentional way to harm people with AIDS and to accelerate their deaths. Whereas most objective readers and viewers are able to discriminate between balanced information and unbalanced rhetoric, many patients have their confidence in their physician's treatment undermined. Although most of the programming and writing correctly encourages an equal partnership between physicians and patients, some of it promotes an adversarial approach.

Gay people have some good reasons to mistrust physicians and medical institutions. Many straight physicians, nurses, and other health care workers are as homophobic as society at large. Until the mid-1970s, homosexuality was classified as a mental illness, and many psychiatrists and other physicians still hold this view to varying degrees. Gay people may have experienced either overt hostility or subtle disapproval when seeking health care in the past. I have personally overheard many disparaging remarks from colleagues, nurses, and medical residents about gay people or people with AIDS. It is no surprise that gay people, with and without AIDS, often approach health care professionals with the expectation that their lifestyle will not be respected.

Nor is it surprising that gay people seeking medical care are not willing to blindly accept the authority of their health care

providers. Gay people grew up in a society where established institutions and authority figures taught them that who and what they were was wrong. During adolescence, gay people begin to become aware of their sexual attraction to members of their own sex. Having been taught their whole life that homosexuality was immoral, sick, or simply laughable, the sexual feelings that gay adolescents experience can be terribly damaging to their self-esteem. The process of self-acceptance often necessitates the rejection of the teachings of religious leaders, teachers, and parents. Gay people who have successfully maneuvered through this painful process have learned to question the established teachings of authority figures. They know they are not always right. It is completely logical that they should apply this lesson to physicians and established medical practice.

It also should not surprise us that gay people are more receptive to nontraditional therapies than to traditional medical treatment. Gay people are frequently said to be living an "alternative lifestyle." For many gay people, the word "alternative" has a very positive connotation, and nontraditional therapies are viewed in a positive light. Many non-Western treatments, such as acupuncture and herbal therapies, may be beneficial and may have a place in the treatment of HIV infection. A balanced viewpoint holds that many alternative therapies deserve further study and that physicians need to keep an open mind about them, but that current knowledge regarding their efficacy and potential toxicity is insufficient.

Unfortunately, some of my patients do not have such a balanced viewpoint. Many patients with AIDS blindly embrace any therapy labeled "alternative," and in my mind, this is at least as dangerous as blind acceptance of traditional pharmaceutical treatment. When I prescribe medication to my patients, I am naturally expected to know and explain the rationale for using the drug, the scientific studies that demonstrate its efficacy, and its potential toxicities. Even when I do, many patients remain reluctant to take medications, especially nucleoside agents such as AZT, which have a bad reputation in both the gay and general press. What amazes me is

that, often, no such scrutiny is demanded of nontraditional therapies, even though these treatments, like pharmaceutical treatments, are sold for profit and have potential for toxicity. Unlike pharmaceutical treatments, most of these nontraditional therapies are not covered by third-party payors, such as Medicaid, AIDS Drug-Assistance Program (ADAP), Blue Cross, and commercial insurance plans. Often, patients of very limited financial means pay large amounts of money out of pocket for therapies with unproved efficacy.

The Challenges to the Physician

I have now painted a picture of a highly politicized group of patients who demand full participation in all decisions pertaining to their health care, who often reject or are suspicious of traditional pharmaceutical therapy, who are highly informed, and who often approach the physician and the health care system as adversaries. The physician who truly wants to serve people with AIDS must be prepared to meet the challenges they pose. The first challenge is to find a compromise between the traditional approach of dictating all care to the patient and the other extreme of allowing a patient to unilaterally decide his own treatment. A physician who is dogmatic or strong-armed will alienate many patients, and those patients will likely go elsewhere for treatment. On the other hand, a physician who is willing to be treated as a vending machine, ordering whatever treatments or tests the patient requests without giving feedback, is doing a grave disservice. We do have specialized knowledge and experience, and our input and opinions are quite valuable. The physician must be willing to give patients a frank opinion while assuring them they will not be abandoned or disliked if they choose not to heed the doctor's advice. The physician must be completely versed in the scientific literature and must be prepared to explain the rationale for a recommendation fully. We also must be patient. Trust is no longer immediately given to us because of our title and position of authority; trust must be earned over time. A patient who is unwilling to heed a

physician's advice on the first visit may be willing to do so after a relationship has been established and the physician has demonstrated both knowledge and genuine concern. We must never be defensive. Patients will shop for doctors, will compare notes with friends who also have AIDS, and will question our management. We must be calm when we explain our decisions and recommendations and avoid becoming angry when we are challenged. Finally, we must be humble enough to admit that although we can help patients to live longer and healthier lives, we cannot as yet cure AIDS. We do not have all the answers.

While we all maintain hope for a cure, those of us on the front lines of AIDS treatment are keenly aware that patients with full-blown disease will most likely deteriorate and ultimately die despite our best efforts. While we may find some solace in telling ourselves that they live longer and have a better quality of life because of our efforts, in our hearts we know that this is not enough to satisfy our patients, their loved ones, or ourselves. For me, as a gay doctor, there is the added burden of feeling that I am failing not only my individual patients, but my community as a whole.

I live and work in Greenwich Village. Although my patients come from all five boroughs and all walks of life, a large number of them are gay men living in either Chelsea or the Village. These men socialize in my circles and frequent the same restaurants, gymnasiums, clubs, and vacation spots that I frequent. I see them on the street, at parties, and on the beach at Fire Island. The converse also is true. Friends and acquaintances turn up in my hospital and in the waiting room of my clinic. There is a certain irony to this. I am a physician in one of the largest cities in the world, yet I sometimes feel like a small-town doctor. I not only know my patients' diagnoses and case histories, I know where they live, who their friends and lovers are, and what they are like socially. I have frequently been at social events where a friend said, "Michael, do you know so and so," only to find that I am being introduced to one of my own patients.

I get a certain sense of connectedness from knowing my patients and being part of their community, but there also is a down

side. I lose the separation between the professional and the personal. It is precisely this separation that enables physicians to cope with the pain and loss they experience when dealing with death and dying. For me, the line separating patient and friend has become blurred, and sometimes nonexistent, and my sorrow is magnified.

Even when I leave work, I can never get away from AIDS. The medicine cabinet in the house I share with friends in Fire Island is filled with AZT, ddI, and Bactrim. During one summer vacation, a housemate and very dear friend asked me what I thought of a purple spot he had discovered on the tip of his nose. I had to explain that it most likely was Kaposi's sarcoma. He died the following March. On vacation with another group of friends last winter, I realized that half of them would be dead within 5 years unless a cure to AIDS was discovered.

The sadness and frustration can be overwhelming. People often ask me, "How can you keep doing what you're doing?" I answer, "How can I walk away?"